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Seeking normality: Parents' experiences of childhood stroke

Christopher McKevitt PhD, King's College London, UK

Marta Topor BSc, University of Surrey, UK

Anna Panton MSc, The Stroke Association, UK

Andrew A. Mallick MBBCh MRCPCH PhD, Bristol Royal Hospital for Children, UK

Vijaya Ganesan MD, University College London, Great Ormond Street Institute of Child Health, UK

Elizabeth Wraige MBBS, Evelina London Children's Hospital, Guy's & St Thomas' NHS Foundation Trust, UK

Anne Gordon PhD, Evelina London Children's Hospital, Guy's & St Thomas' NHS Foundation Trust, UK

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Introduction

Stroke is typically associated with older adults but also affects children, from the perinatal period onwards. Incidence of pediatric stroke has been estimated to range from 1.2 to 13 per 100,000 children <18 years old (Mallick & O'Callaghan 2010, Tsze & Valente 2011); and there are multiple causes including vascular, cardiac and blood disorders, infection and trauma, with around 10% of unknown origin (Greenham et al. 2015).

Work by Greenham et al (2015) has synthesised the literature on outcomes for this population, reporting that: estimates of death range from 7-28% (ischaemic stroke), and from 6-54% (haemorrhagic stroke); estimates of recurrence rates range from 6-35%; up to 20% of those with ischaemic and around 17% with haemorrhagic stroke develop epilepsy; and a range of negative impacts on motor, cognitive, psychological and social outcomes have also been reported.

Contrary to assumptions, children may not recover from stroke better than adults. Whereas stroke in adults can result in changed levels of functional ability, stroke in children leads to a changed ability to achieve functional ability (Greenham et al. 2016). These authors argue that stroke in children leads to a greater 'lifelong individual, family and societal burden' (Greenham 2016: 1159) because they may face more years of life with disability.

In the United Kingdom children who have had a brain injury may be seen at National Health Service (NHS) tertiary level specialist children's hospitals. There are very few specialist inpatient rehabilitation providers and the majority of children are supported by therapy services providing care at home and in education settings. The NHS also coordinates and delivers community pediatric medical and therapy services and child development centres.

Numerous studies have considered the met and unmet needs of children (and families) with other long-term conditions, such as traumatic brain injury, cerebral palsy and cancer. For example, high levels of unmet needs for health care have been reported in children with cerebral palsy (Jackson, Krishnaswami & McPheeters 2011). However, needs may vary according to the specific condition and its sequelae. Parents of children with cancer have reported being very satisfied with the continuity of clinical care that their child received but not with needs for emotional support (Mitchell, Clarke, & Sloper 2006). In contrast, parents of children with autism ranked continuity of service provision very often not met, while the need for counselling as the least important and the least likely to be unmet (Brown et al. 2012).

The severity of the condition and the child's age may also influence type of needs identified and likelihood of these being met. Mitchell, Clarke, & Sloper (2006) reported differences in how well

young people with cancer felt the ward environment was appropriate according to the age of the patient. Other studies have reported that number of unmet needs reported by parents increases according to the severity of the child's condition (Palisano et al. 2010, Jackson, Krishnaswami & McPheeters 2011).

There may also be differences in how parents and children report needs. For example, one study of young people (12-18 years of age) with mild traumatic brain injury and their parents reported that parents highlighted the need for better communication between clinical and school services to assure good academic support, while the young people were more concerned about the medical support they received post-injury (Gagnon et al. 2008). As Nelson et al. (2012) have documented, many studies have considered the specific experiences and needs of parents of children with long terms conditions, with similar needs for emotional and social support, concerns about access to well-co-ordinated children's services, and needs for information provision.

Many studies have used qualitative methods to explore the experiences of adults with stroke, and of their family carers. These have focused on a range of topics including experiential reports of the stroke event, and its consequences; perceptions of clinical and social care provided; identification of needs as perceived by patients and their families and studies, specifically undertaken to develop or evaluate interventions (McKevitt et al 2004). However, we are aware of only one other study that has explored the experiences of families where a child has had a stroke. Souvri et al 2017 found that parents reported a lack of information, feeling abandoned after discharge from hospital, a focus on functional recovery, with hidden disabilities only being recognised later, and a need for psychological support. Our interview study similarly aimed to document family's experiences from their own, rather from a clinical perspective, to identify perceptions of quality of care received, as well as the strategies parents used to support their child. Our purpose was to use this information, alongside estimates of unmet needs derived from a survey of children with stroke and their parents (Authors) to inform the development of pediatric stroke services, and to ensure alignment between professionals' priorities and service users' needs and preferences.

Methods

Participants were parents of children with stroke recruited from three regional specialist services in England to take part in the survey who had previously taken part in our needs survey. They were sampled using criteria of interest including age of the child at stroke onset and time since first stroke and invited to take part in a follow-up semi-structured interview. A specially developed topic guide was used to introduce topics of interest and to allow participants to raise their own concerns. Two parents and one young person affected by stroke in childhood reviewed the topic guide, suggesting some minor amendments. Seven interviews were face-to-face and five were by telephone, at participants' request. All were undertaken by a member of the study team not involved in the clinical care of the child. Interviews were audio-recorded with permission and lasted between one and two hours.

Interviews were professionally transcribed in full for analysis. Three members of the research team contributed to data analysis. Thematic analysis was conducted following Brown and Clarke's (2006) guidelines for deliberate and rigorous analysis. The transcripts were screened for a wide range of patterns and subsequently coded line by line. This allowed a rich thematic description of information relevant to the aims of the study. The themes were generated on a semantic level using the realist method to reflect patients' and families' experiences from their point of view. Prevalence of themes and sub-themes within all of the transcripts was monitored to facilitate the identification of interviewees' concerns.

Ethical approval for the study was obtained by London-Chelsea Research Ethics Committee (Ref: 14/LO/0070).

Results

Participants

Twelve out of 13 parents invited to take part were interviewed (one declined as it was not convenient for their family at the time). Their children varied in terms of ages at stroke onset, time since stroke and current level of neurological deficit, using the Recovery and Recurrence Questionnaire (RRQ) (Table 1). This multi-domain assessment tool provides a global score from 0 (no deficit) to 10 (profound deficit) across 5 domains of function: left and right sensorimotor, expressive and receptive language, and cognition/behaviour. Five children had no or mild deficit and seven had moderate to severe deficit.

We report the main themes from the analysis. Four were in response to specific questions asked in the interview: how the stroke was thought to have affected the child; the impact on the family; participants' views of the quality of clinical care; experiences related to education. A fifth theme was identified from participants' narratives: the desire to construct a sense of normality.

Impact on children

Asked to describe how the stroke had affected their child, parents' accounts varied widely from those who reported that the consequences were mild or minimal, to those which were severe and distressing. Eleven parents reported that their children sustained physical consequences of the stroke commonly reported in the literature (such as hemiparesis and reduced mobility) as well as others less commonly reported, including problems with posture, clumsiness and fatigue. Thus while some children were classified as having no or mild neurological deficit, most parents reported sustained physical consequences for their child in functional tasks.

... in terms of physical ability, it's made a difference. It seems a bit harder for her. I'd say more co-ordinated activities such as, they did a sponsored skip at school the other week, which she was noticeably poorer at than the other children. And she's found it harder to do fine motor skills etcetera, though that has really improved. The thing she finds really hard now is using a mouse, actually, on the computer.

Interview 4

Psychological and emotional problems reported included suicidal ideations and episodes of self-harm, aggressive behaviour, low mood, feeling uncomfortable about disability, anxiety, changed personality and low motivation to take part in therapy and to interact socially.

Five parents discussed the impact on their child's cognitive status, including their slower than expected ability to process information, memory problems, speech and language abilities and developmental issues such as toilet training.

"So she just needs a bit more time to process information and work out her response..."

Interview 4

Parents were concerned also about the impact on their child's social participation, which was attributed both to the physical and psychological consequences of stroke and to others' perceptions of the child affected by stroke. Similarly, a child's ability to take part in leisure activities could be affected by their physical ability or tendency to tire easily. Two parents reported concerns about the negative impact of the stroke on their child's academic performance.

Impact on family

In this sample, the time between (suspected) incident stroke and confirmation of diagnosis varied considerably, yet news that the child had had a stroke was inevitably described as shocking or stressful.

Certainly, at the time when [daughter] had her stroke it had a huge impact on me and the whole family. In some ways you don't realise it because it's the last thing you're thinking about or care about, but yeah it had a very big impact on me.

Interview 6

The shock was not simply related to the distress of the child being seriously ill, but also that the illness was stroke, not something any of the interviewees had previously been aware of affecting anyone other than older people

Some parents described continuing to feel worried, anxious or stressed about what stroke meant for their child's future health and life. A minority referred to feelings of guilty because of potential connections between the stroke and family genetic conditions, or a more general concern that the stroke had occurred because of something a parent did or did not do. Several parents spoke of experiencing sleepless night or periods of tearfulness, with one reporting having clinically diagnosed depression linked to the severe difficulties she and her daughter with stroke were experiencing. Two parents with existing long-term conditions reported how caring for the child with stroke exacerbated their own health problem.

Some spoke of the ways in which demands to care for the child with stroke led to tensions in family relationships, made manifest as resentment from other siblings, disputes and, in one case, marriage breakdown.

For some there were financial impacts, resulting from taking long periods off work while the child was in hospital, for example.

Perceptions of the quality of clinical care

Parents were asked to comment on the quality of care received. Where the child's stroke onset was not perinatal, parents described problems being admitted to hospital either in relation to ambulance services' failure to recognise this as an emergency or because of general practitioners' perceived reluctance to refer the patient to specialist services. However, interviewees were generally satisfied with acute hospital care received, with one exception, where the child had been admitted to a small hospital and the parent believed that staff had been negligent. They were also positive about the input of therapists during in-patient care, although some described confusion about the role of multiple staff members involved.

... we saw a lot of people and had a lot of people introduce themselves to us and they do start by saying 'Hello my name is so and so and I'm a blah, blah, blah' but you can't always take that in. And you have a conversation with someone and then they disappear and often my husband and I would look to each other and say, 'Who was that?' and we'd have no idea.

Interview 1

Those who discussed the discharge procedure were critical of how poorly prepared they felt for what lay ahead. In retrospect, they reflected that they had been given insufficient information about how to care for their child at home, or what services might be available to support them. Where they discussed discharge summaries, they described these as too medical to be useful:

I mean again they are quite detailed but they're quite medically detailed because I think they're for the GP and they just send them to the parents.

Interview 1

Most parents were satisfied with the therapies their child had received in the community, and in some cases, with the input of therapists in assessing needs in nursery or school. However, some

reported delays in accessing community therapy services, and some identified limitations in what was available:

At the moment, and this is purely down to constraints of money in the community network have provided for (child), we don't have any occupational therapy in the community at all and we have quite limited physiotherapy input.

Interview 5

Parents reported their own involvement in therapy, actively carrying out or supervising exercises with their children, even if some felt ill-equipped to do so or felt that the child responded better to a professional's direction. Four interviewees reported paying for therapies outside NHS provision because they felt dissatisfied with the amount of therapy their child had received, because they believed that more therapy would accelerate recovery, or because they were attracted by the techniques private providers offered.

In general, there was dissatisfaction with primary care input. This was largely related to GPs' perceived low levels of knowledge of pediatric stroke but also because of the view that regular appointments or and check-ups were not offered, when this was perceived by interviewees as useful or necessary.

Most parents whose child had emotional/psychological difficulties reported that it was difficult to access professional input. They reported a need for advice on the child's emotional or behavioural issues, especially where a child was entering teenage years. Where children had accessed psychology services, this tended to be via other medical services the child was using, such as a sickle cell service.

Education

Children with long term conditions may face particular problems in relation to education. In England and Wales, Special Educational Needs and Disability Regulations 2014 provide a statutory framework for the assessment of needs and provision of support (such as progress reports, extra help with learning, aids), or if deemed necessary, an Education Health and Care plan which may also provide financial support. Schools are required to designate a teacher to act as Special Educational Needs

Coordinator (SENCO) who undertakes training in special educational needs and has overall oversight over practices to ensure that needs for special education are met by the school.

Parents were asked to describe the experience of the child's starting or returning to formal education after stroke. Both positive and negative experiences were described. Positive experiences were attributed to the school in question having established and experienced programmes for children with additional needs, where therapy staff were involved in risk assessment, where education support staff were in place and able to intervene, or where individual staff demonstrated that they were willing to identify solutions to the particular needs of the child and family. For example, one parent reported:

[The nursery staff] have been quite helpful telling us that they've got a settling in programme and if we need to take longer with [child] then we can.

Interview 2

Negative elements of the return to school included delays in the child being able to return to education because of the time needed to assess and make suitable arrangements; the fact that a child's educational and cognitive support needs in school might only gradually become apparent, and might change over time; uncertainty about how to help the child adjust to the increased burden of being in a learning environment after time in hospital; limited access to psychological support for children with emotional or behavioural problems, or for those experiencing bullying; and the time at which the child needs to return to school: one child was discharged from hospital during the summer vacation, – leading to difficulties in accessing key school staff for planning support needs. Again, a school's familiarity with special education needs and stroke in particular was seen as an important factor:

I think most schools are used to dealing with, like, ADHD, autism, behavioural things, asthma, and I suppose, if a child is born with a condition, those things are already in place when the child goes into the school. But when you're suddenly gone, 'Here's this child with special needs...the schools go, 'Oh, my God. What are we going to do?'

Interview 7

With one exception, parents reported positive experiences of the service provided by the SENCO, describing good relationships, useful sign posting to existing services and support negotiating access to education.

Defining a child's needs was not always straightforward. One parent described how the special provisions agreed but the authorities were deemed insufficient by the school itself:

The first time they gave him 20 hours. The headmaster called me and said I shouldn't accept 20 hours; that I should tell him that it's a full statement – 35 hours – or nothing. So we had to go back to [the local authority] and tell them no, we can't – that he needs support on the playground, as well.

Interview 9

Parents were also proactive themselves in overseeing the support a child might need, taking on the role of updating and refreshing information each school year:

I tend to go in at the beginning of the year and say, 'Can you remind the teachers?'

Interview 6

Some interviewees took it on themselves to address what they saw as low levels awareness of pediatric stroke among school staff. Parents stressed the importance of teachers knowing that their child had had a stroke but also how this might affect their learning abilities and their ability to concentrate. As parents, remarked these could be considered invisible disabilities, so might not be immediately apparent. One mother described her own son's situation:

So like every new teacher that he comes into contact with we kind of – or every kind of out of school activity person we kind of explain what's happened and just say, 'He will get very teary and that's what [Hospital 1] said to expect.'

Interview 8

Some also provided the school with information resources about pediatric stroke; one had designed a training package to be cascaded and shared amongst school staff, while another had designed a one-page factsheet for school staff.

Some semblance of normal: situations and strategies

The accounts of these parents emphasise the priority given to finding or constructing a sense of normality for their child and for the family. Children's abilities and behaviour were observed and assessed in relation to parents' normative expectations about children of their own child's age. They spoke of trying to get back to normal or envisaged a future for their children where they could ... *grow and develop as much as in inverted commas "normal" children do... to have access to the same things that a normal child does.*

They also had questions about what might be normal for a child with stroke, since this knowledge could help them to form their own expectations and inform others (teachers, for example) about what to expect. As another parent put it:

So for us it's what's stroke related, what's small boy, what's him – so yeah, that's probably the hardest thing for us.

Interview 8

However, achieving a sense of normal was not straight forward. For example, there might be a balance between helping the child and promoting the child's independence. One parent described the 'caring' role that her daughter had adopted for her brother who had had a stroke, with concern that this was reinforcing the neediness of the boy and encouraging him to take advantage of his sister's kindness, rather than acting independently. Another described the dilemma she felt in terms of the child's place of education, where she might stand out as different:

... we're desperate for [Child] to go through mainstream school because we think it's the best thing for her but it's also got to be, you know, it's got to work in a classroom environment as well so you're very aware that you don't want any disruptive behaviour that's going to disrupt other children as well.

Interview 5

In their efforts to creating some semblance of normal, parents required information on a wide range of topics and tried to draw on social support from existing social networks of family and friends, from relevant community-based organisations and from other families in the same situation.

Our survey of unmet needs after pediatric stroke identified information as the largest area of unmet need, even though all participants had been in contact with specialist clinical services (Authors). The interviews shed some light on why parents may have felt that their information needs continued to

be unmet, with concerns about information from the onset of stroke and beyond. Around half of interviewees were unhappy with the provision of diagnostic information, related to initial misdiagnosis, lack of satisfactory explanation of the diagnosis, or dissatisfaction with how the diagnosis was communicated.

The way we were told about his condition, it was quite blunt and abrupt, and we had no information... So it was more of a case of us trying to find out.

Interview 2

Beyond the need for diagnosis, a process of naming the problem, parents also identified a need for an explanation of the implications of the stroke. Around half of interviewees felt they weren't given sufficient information about stroke in children, what to expect in the future, or what this meant in terms of the child's education, for example. Some identified the need for a single point of contact after discharge from hospital to ask for information and advice as new questions arose, or new problems emerged. Most parents reported that they were not provided with information about sources of support available to them after discharge from hospital, nor how to manage problems that subsequently became evident, such as behavioural or psychological problems.

Because you need to know what's available in your area because otherwise you just spread yourself so thin that you wouldn't know where to go.

Interview 3

Most interviewees described proactively trying to find out information about childhood stroke, usually using the internet. Some reported this as a successful strategy help them to learn more about stroke, for example but others found it stressful, confusing or worrying and had concerns about the reliability of the information they found.

Participants' existing social networks for wider family and friends were an important source of support, with one participant commenting of her own parents and friends,

They were very supportive. They never saw (child) as being different and, definitely helped her in everything she was doing, and making sure that there was no difference between how they would treat a grandchild to another one, or friends different from their children.

Interview 3

Other however described difficulties with family members who were unable to offer meaningful support because of their own anxiety about the diagnosis, lack of information, and the implications for their own children's health considering the genetic implications of stroke in children.

Most interviewees had had the opportunity to meet other families in the same situation and were more unequivocal about the support that this had provided them. This support took the form of opportunities for exchange of experiences and information as well as feeling understood and not alone. The reciprocal nature of these encounters was also reported:

So sometimes when you have a bad day you can have a bit of a whinge or talk about medication or therapies or statements for school and, you know, we're all going through the same sorts of things and it's nice to give a bit of advice and also get a bit of advice.

Interview 5

Meeting other children who had had a stroke was also seen as useful in terms of being able to see how other children are affected and how parents managed with their own children. Most interviewees also thought it was useful for children with stroke to meet each other, although some reported that it was less useful if the age difference between children was too great or that it could be an uncomfortable experience for children whose disabilities were less severe or obvious than others'.

Despite the difficulties in finding out about community-based services that were available, interviewees identified a range of community and voluntary sector organisations that had provided information, resources for therapy and education, respite care, activities for children and meetings for parents.

Discussion

This study investigated parents' experiences of caring for a child with stroke to inform the development of support services informed by their needs. Overall, parents' accounts articulate the profound impact that pediatric stroke can have not only on the individual child but also on the family. As Souvri et al (2017) have reported, the unexpected nature of the stroke occurrence was profoundly disturbing, compounded by parents' lack of awareness that children, as well as older people could have a stroke. In addition to consequences for the child's health, abilities and development, parents discussed the impact on the family as a whole. In terms of quality of care, parents were generally satisfied with the acute specialist care that their child received but

experienced problems after discharge as they encountered challenges as they sought to meet their own and their child's needs and sought to achieve 'some semblance of normal'.

As has been reported in adult stroke (McKevitt et al 2011, Rodgers, Bond & Curless 2001), and by Souvri et al (2107) in the case of pediatric stroke, participants in this study were dissatisfied with information provision. This included concerns about the content of information, its timing, and the clinical style of communication used. Additionally, they reported that it was not clear how to access information to address new needs that emerged over time.

Parents' experiences with ensuring their child's progress in education varied widely. Legislation in England requires local authorities to assess and support children with special educational needs but parents' accounts suggested that where schools had prior experience of meeting special education needs or where individual staff members were proactive managing a child's case, their experience was more positive.

Family was identified as a key source of support for parents. Yet interviewees also reported negative impacts on the family ranging from feelings of guilt, tensions in family relationships to negative effects on physical and mental health, marriage breakdown and financial consequences. Knowing how to get help was difficult. However, it also important to recognise that parents were proactive in seeking to meet the challenges they faced. They used available resources such as the internet and community groups, sought out others in the same situation to seek and exchange information and moral support. Some even took it on themselves to provide schools, for example, with information about pediatric stroke and its consequences.

As has been reported for adult stroke, meeting post-acute needs requires the ability to navigate a new and not always visible field (Sadler et al 2014). Overall, the accounts of parents in this study are characterised by variations in need and success in meeting these, according to the specific stroke sequelae the child experience but also the resources individual families had and the medical and social resources available in the area where they lived.

This was a small scale study, using one-off interviews with limited sample of parents recruited from specialist centres, active in stroke research. Although we had planned to interview children themselves, we were only able to recruit two young people and their data have not been included in this analysis. Although we used a purposive sampling strategy to ensure variation by age at stroke and time since stroke we were not able to sample by other characteristics which may be important such as socio-economic status, ethnicity, or the child's comorbidities. Nevertheless, our study

provides new information about the experiences of parents with stroke, which complements existing focus in the literature on clinically defined outcomes of pediatric stroke.

Our study has a number of implications for practice. While acute stroke care was perceived to be good, problems were identified once a child was discharged home. This suggests a need for better coordination of information and care provision across sectors. It also highlights a need to raise awareness about pediatric stroke and its consequences among community-based professionals in health, social and educational fields. Families also require improved access to information and for different kinds of information as a child develops. The wide variations in unmet needs reported here suggests a need to set standards of care across the pathway. A recently updated clinical guideline for pediatric stroke (RCPCH, 2017) provides a benchmark for care which could be used to assess and improve the quality of provision.

Key messages

- Stroke in childhood is experienced as a shocking and unexpected event by parents since this condition is commonly associated with aging.
- Parents reported a widespread lack of awareness of pediatric stroke, which was thought to influence the ability of services to meet the needs experienced by children and families.
- Parents reported positive experiences of acute pediatric stroke care and community rehabilitation; variable support to meet a child's educational needs; and poor experience of primary care.
- Access to information to help parents address the multiple and emergent needs of their child, themselves, and the family was lacking but support from and information exchange among peers was valued.
- Parents' priority was to establish a sense of normality for the child and themselves and they were proactive in seeking ways of doing this.

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Table 1: Characteristics of children with stroke

Interview no.	Child's age at time of stroke	Time since stroke	Current total RRQ score
1	Neonate	Within one year	0
2	Neonate	Within five years	1.5
3	Neonate	More than five years	0.5
4	3 years 11 months	Within one year	1
5	10 months	Within five years	4
6	18 months	More than five years	0.5
7	10 years 2 months	Within one year	4
8	5 years 10 months	Within five years	0
9	6 years	More than five years	1.5
10	11 years 10 months	Within one year	2.5
11	15 years 5 months	Within five years	2.5
12	13 years	More than five years	0